

# Living With Heart Failure

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Adapted from "Living Successfully with Heart Failure Program," Barbara Riegel, Sharp Healthcare.



## Living With Heart Failure

Many people with heart failure are able to lead normal, active lives. This book is intended to help you learn to live well with heart failure. We want you to learn about your body, the disease, and the way heart failure is treated. You can help control your heart failure by carefully following your care plan and taking good care of yourself. If you do so, you too might be able to lead a normal, active life.

### What is heart failure?

Many of us think that heart failure means that the heart has stopped, but heart failure means that the heart fails to pump as well as it should. When the pump (your heart) becomes weak, fluid that should be pumped out of the heart backs up into the lungs. Fluid backing up into the lungs causes congestion, which is why it is often called "Congestive Heart Failure." Fluid might also back up into other parts of the body. This is why many people with heart failure have shortness of breath and/or swelling in the hands, legs, ankles, and feet.

### Causes of heart failure

Heart failure often occurs when another problem makes the heart weak. Coronary artery disease (blockage in the heart arteries) is a common cause of heart failure. Other causes include heart attack, high blood pressure, infection of the heart muscle, problems with the heart valves, and lung disease. Sometimes, the exact cause of heart failure is not known.

Ask your doctor or nurse what causes your heart failure. Based on the cause of your heart failure, there could be special things that you can do to care for yourself that are not included in this book.

The cause of my heart failure is:\_\_\_\_\_

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## How does it feel to have heart failure?

### People with heart failure often have:

- Shortness of breath, wheezing, or coughing with activity
- Problems with breathing when lying down
- Waking at night feeling short of breath or coughing
- Weakness, tiredness
- A feeling of/or being "out of shape"
- Swelling of hands, legs, ankles, feet, or stomach

### What should concern me?

**Do not ignore any worsening symptoms.** Call your nurse or doctor if you have or feel:

- Weight gain of 2-3 pounds overnight or 5 pounds in a week
- Extreme shortness of breath or more shortness of breath than usual with activity or rest
- The need to use more pillows or to sit up in a chair to breathe comfortably at night
- Periods of waking from sleep due to shortness of breath and needing to sit up to catch your breath
- More tired than usual from everyday activities
- Unable to be as active as you were in the past
- A cough without any flu-like symptoms
- Swelling of hands or rings begin to feel tight
- Swelling of feet or ankles or tight shoes
- Upset stomach or loss of appetite

## Taking care of yourself

There are things you can do to make it easier for your heart to pump well and to help you feel better. Make this plan a permanent part of your life.

**To best take care of your heart, you should:**

- Take your medications exactly as directed.
- Follow a low sodium diet.
- Weigh yourself every day. Your body weight can change from day to day.
- Get regular exercise.
- Maintain a normal body weight.
- If you smoke, stop now. Smoking has a very bad effect on your heart.
- Drink little to no alcohol. It is best not to drink any alcohol.
- Avoid drinking excess fluids.
- Know when to consult your nurse or doctor.

## Medications

- Take your medications as directed by your doctor. Never change or stop a medicine without checking with your doctor first. It can be dangerous to stop some medicines quickly.
- If you forget to take a dose, take it when you remember, if it is within a few hours. If you don't remember until it is time for the next dose, do not take a double dose.
- Medication organizers or pillboxes can help you to take your medicines routinely. These are sold at most drug and grocery stores.
- Keep your medicines in a cool, dry place. Avoid the bathroom. Except for those pills in your weekly pillbox or organizer, keep medicines in the original prescription bottles.
- Keep an updated medication list and carry it with you to all your doctor or nurse visits. Include the dosage. Your doctor or nurse can help you with this, if you would like. If there is any doubt about the medications, take all your medicines to your next appointment and ask your doctor or nurse to go through the medications with you so that you understand which medications you should take.
- Check with your doctor, nurse, or pharmacist before taking over the counter medications and herbal supplements. These can change the way your prescription medicines work or may cause more side effects.

### Medications often given for heart failure include:

- Blood Vessel Dilators [Angiotensin Converting Enzyme (ACE) Inhibitors and Angiotensin Receptor Blockers (ARBs)] – relax the blood vessels allowing more blood to flow through the vessels and help your heart failure from getting worse.
- Diuretics – also known as water or fluid pills help rid the body of extra fluid.
- Potassium – mineral that helps control your heart rhythm.
- Digoxin - works to strengthen the pumping of the heart.
- Beta-blockers – reduce how hard the heart works.
- Direct-acting Vasodilators – make the blood flow to the heart better.

## VASODILATORS

### ACE Inhibitors (Angiotensin Converting Enzyme)

ACE inhibitors make the blood vessels relax and expand. This allows the blood to flow through the vessels with less work on the heart. The heart does not have to pump as hard. ACE inhibitors also control blood pressure and protect the kidneys in some conditions. Over the long term, they could help patients with heart failure live longer. Some of the medicines in this group are:

Lisinopril	Prinivil, Zestril
Enalapril	Vasotec
Captopril	Capoten
Fosinopril	Monopril
Quinapril	Quinapril

These drugs could cause a dry cough. Call your doctor or nurse if this becomes a problem for you. ACE Inhibitors can cause a very rare but serious condition called angioedema. This is a swelling of the lips, tongue, and throat. If you get this, do not take the medicine and call 911 or get to the emergency room right away.

### ARBs (Angiotensin Receptor Blockers)

Some patients who can not take ACE inhibitors may be on similar medicines called ARBs (Angiotensin Receptor Blockers). They also relax the vessels and may help the heart pump better. Over the long term, they also could help patients with heart failure live longer. Some of the medicines in this group are:

Losartan	Cozaar
Irbesartan	Avapro
Candesartan	Atacand
Valsartan	Diovan

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### DIURETICS

Diuretics, or water pills, help your kidneys make more urine and get rid of excess salt and water. This results in less fluid for your heart to pump. With less to pump, the heart does not need to work so hard. Also, it will reduce the fluid backing up into the lungs and will help to make your breathing better and will decrease your swelling. Water pills include:

Furosemide	Lasix
Chlorothiazide	Diuril
Hydrochlorothiazide (HCTZ)	Oretic, Esidrix, Ezide
Bumetanide	Bumex
Torsemide	Demadex
Metolazone	Zaroxlyn

Metolazone is a very strong water pill and most patients only need it every once in a while as advised by the doctor/nurse when they are not responding well to other water pills. There are some diuretics that also help your kidneys to produce more urine and help your body hold on to potassium, so you may not need to take potassium pills. These are called potassium-sparing diuretics. Potassium-sparing diuretics include:

Amiloride	Midamor
Spironolactone	Aldactone
Triamterene	Dyrenium

Along with more frequent urination, you may feel thirsty. Thirst and urination are normal effects of diuretics. But, call your doctor or nurse if you are taking diuretics and have:

- Dizziness
- Severe weakness
- Severe leg cramps



### **POTASSIUM**

Potassium is a mineral that your body needs. It helps to control your heart rhythm. Some water pills cause you to lose potassium (KCl), along with urine. If this happens, you might need to take extra potassium. Brands of potassium include K-dur, Micro K, or KCl.

Potassium pills could cause an upset stomach. To avoid this, take the potassium with a full glass of water, either with your meal or right after eating.

Ask your doctor if it would be helpful to include foods which contain more potassium in your diet. Some patients with kidney problems should not eat foods high in potassium. Some salt substitutes are largely composed of potassium.

Foods high in potassium and low in sodium include:

- raisins, prunes, apricots, figs, dates
- bananas, cantaloupe, grapes, oranges, honeydew melon, and orange juice
- potatoes, beets, greens, spinach, peas, beans, tomatoes, mushrooms. Avoid canned foods unless labeled "low sodium."
- broccoli, cauliflower, and squash
- flounder and halibut
- fresh turkey or beef

### **DIGOXIN**

Digoxin, also called lanoxin or digitalis, is usually taken once, early in the day. Digoxin increases the pumping strength of the heart and helps to control the heart's rhythm. Call your doctor if you feel any of these possible side effects from Digoxin:

- Loss of appetite, distaste for food, or bad taste in the mouth
- Upset stomach or vomiting
- Bluish or yellowish vision
- Skipped heart beats, palpitations, or rapid heart beat
- Dizziness

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### BETA-BLOCKERS

Beta blockers slow the heart rate, which leads to a decreased need for blood and oxygen to the heart and reduces how hard the heart must work. They also help the heart beat more regularly and help control high blood pressure. Over the long term, they could increase the pumping action of the heart and help patients with heart failure live longer.

Beta-blockers are often used along with ACE inhibitors, diuretics, and Digoxin. Some of the medications in this group are:

Carvedilol	Coreg
Metoprolol	Lopressor, Toprol XL
Atenolol	Tenormin

Side effects may include dizziness, lightheadedness, unusual tiredness or weakness, and/or increased difficulty breathing. When you first start these pills or their dose is increased, you may feel more tired than before or swelling may increase requiring slightly higher doses of the diuretics or fluid pills. If you are able to tolerate the first 4-6 weeks, then these problems will usually get better.

If you are taking Coreg (Carvedilol) and an ACE inhibitor, take the Coreg (Carvedilol) 2 hours before or after your ACE inhibitor and with food.

### DIRECT ACTING VASODILATORS

Direct-acting vasodilators include nitrates and hydralazine. These improve blood flow to the heart and also decrease the load against which the heart has to pump.

Nitroglycerin SR Caps	NitroBid, Nitroline
Nitroglycerin Transdermal	Minitran, Nitro-Dur, Nitrodisc, Transderm Nitro, Deponit
Isosorbide Dinitrate	Isordil, Sorbitrate, Dilatrate SR, Iso-Bid, Isotrate Timecelles
Isosorbide Mononitrate	ISMO, Imdur
Hydralazine	Apresoline

Some side effects may include headache, dizziness or lightheadedness when you stand up, nausea, vomiting, restlessness, flushing of the face, or fast pulse.

## Low Sodium Diet

Limiting your sodium is a key part of your treatment. In general, you should eat no more than 2 grams or 2000 milligrams of salt every day.

**Do not use table salt. Table salt contains mostly sodium. Just one teaspoon of table salt contains about 2 grams of sodium.**

Give yourself time to get used to eating a low sodium diet. It takes a while for your taste to adjust to less salt. As you adjust, you may find that foods are more flavorful in a different way.

Sodium is also found in many canned, pickled, or prepared foods. As a general rule, follow these suggestions:

- Eat fresh fish, meats, and vegetables.
- Avoid convenience foods like hot dogs, luncheon meats, canned soups, and frozen dinners.
- Do not add salt to your food at the table or in cooking.
- Season with herbs, garlic, onion, and lemon.
- Avoid salts like garlic salt, seasoned salt, and onion salt. Try garlic powder, or fresh onion or garlic.
- Rinse and drain canned vegetables, tuna, or salmon before eating or use products low in sodium.
- Avoid foods that are high in sodium (see list on page 11).
- Eat only small servings of foods moderately high in sodium (see list on page 11).
- Read all labels for salt, sodium, or sodium products. Look for labels that say "salt free," "low salt," or "low sodium."
- Be aware of hidden sources of sodium (such as MSG or "Accent®," sodium benzoate, sodium caseinate, sodium citrate, sodium saccharin).
- Choose sodium-free antacids if needed – ask your doctor or pharmacist for help with this.

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## Reading Labels

First, look at the list of ingredients. The largest quantity is listed first and the smallest amount last. For example, a jar of sweet pickles lists the ingredients as "cucumbers, water, corn syrup, vinegar, peppers, salt, natural and artificial flavors, preservatives, and artificial coloring." This tells you that cucumber is the main ingredient, water the next highest, and so forth. Avoid products in which sodium is listed in the first few items. Try to buy items labeled low-sodium or no salt added. **Foods with less than 140 mg per serving are considered low sodium.**

Then look at the "nutritional information per serving." This section lists the amount of calories, protein, carbohydrates, fat, and sodium in one serving. It also tells you how much of the product is one serving. Your normal serving may be smaller or larger than what the package refers to as a serving. For instance, one normal serving of milk is 1 cup. But, if you pour the milk into a tall glass you might have more than 8 oz. (1 cup). If your portion size is double the size listed, remember to double all the nutrition information listed.

**Avoid these high sodium foods:**

- Frozen "TV" dinners
- Canned beans and franks
- Pancakes/waffles
- Processed cheese (Velveta, etc.) and hard cheeses (cheddar, swiss, etc.)
- Packaged snack foods (chips, pretzels, pork skins)
- Soy sauce, teriyaki sauce
- Cooking wine
- Bouillon cubes
- Canned or packaged soup, broth
- Olives and pickles
- Canned vegetables
- Sauerkraut or vegetables in salty brine
- Frozen vegetables with sauces
- Tomato juice, V-8® Juice
- Celery salt, onion salt, garlic salt, seasoned salts, MSG (Accent®), sea salt, meat tenderizers
- Athletic drinks (Gatorade®, thirst quencher)
- Canned, smoked, or salted meats (like ham, bacon, sausage, corned beef, hot dogs, and SPAM)
- Luncheon or deli meats (such as bologna, salami, luncheon loaf, turkey roll/chicken roll)
- Salted fish
- Softened water
- Hamburger Helper, Tuna Helper, Macaroni & Cheese, and other packaged mixes

**Eat only small servings of these foods that are moderately high in sodium:**

- Bottled salad dressing or salad dressing mixes
- Mayonnaise
- Steak sauces
- Catsup, mustard
- Chili sauce
- Dips and party spreads
- Cake, doughnuts, fruit pies, biscuits, muffins
- Egg substitutes
- Pizza
- Buttermilk
- Baking powder
- Baking soda
- Self-rising flour and corn meal
- Cottage cheese
- Instant pudding
- Some instant and dry cereals

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## Eating Out

Eating out offers new challenges when following a low sodium diet. A sit-down restaurant offers more low sodium options than you will find at a fast-food restaurant. Check the menu and ask questions. Avoid foods that are high in sodium and ask if food can be cooked without added salt.

**Avoid foods that are described as:**

- Fried
- Creamed
- Au gratin
- Buttery
- Escalloped

Also avoid foods that are prepared with soy sauce or MSG. These are often found in Oriental foods. Ask for steamed vegetables in place of french fries or a fruit salad in place of coleslaw. Order all dressings and sauces on the side.

Biscuits, croissants, and muffins often contain higher amounts of fat and sodium. You may ask your server not to bring bread to the table until you have your meal so you are not tempted. Melba toast and whole wheat rolls are better choices if they are offered.

**Order foods that are:**

- Steamed
- Broiled
- Grilled
- Roasted
- Stir fried

Following these guidelines allows you to enjoy your food when eating out while you take care of your health.

## Daily Weight

Weigh yourself every day. A sudden weight gain is one sign that you might be retaining fluid. What was your weight on the day you were discharged from the hospital? This is probably your ideal fluid weight. I weighed \_\_\_\_\_ pounds on the day I came home from the hospital.

- Weigh yourself first thing in the morning (after you urinate, but before you eat breakfast and before you have a bowel movement).
- Think about how you have been eating. Are you eating less and losing fat pounds? If you are eating less but not losing weight, this may mean fluid is building up in your body.
- Enter your weight into your weight diary or on your calendar each day. Bring this record with you when you visit your doctor.
- If you have a weight gain of 2-3 pounds overnight or 5 pounds in a week, call your nurse or doctor. It may mean you need a change in the type or amount of medicine you are taking.

If your weight increases by \_\_\_\_\_ lbs over \_\_\_\_\_ days take an extra \_\_\_\_\_ mg of lasix a day until your weight decreases to \_\_\_\_\_.

## Exercise

We used to believe that people with heart failure should rest, rest, rest. Now, we know that regular exercise is needed. Spending large parts of the day in bed can weaken you. Recent studies show that people with heart failure can exercise safely. In fact, regular exercise could improve your ability to function, decrease your symptoms, and strengthen your heart.

There are certain things you can do to conserve energy in order to remain active in your daily routine and get enough exercise.

- Do not hold your breath when walking, exercising, or doing any kind of physical activity.
- Try taking rest breaks. This will prevent you from getting too tired.
- Use slow, smooth, flowing movements. Rushing only increases fatigue and discomfort.
- Exercise at the time of day when you are at your best energy level. Think about your best time for activity.

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- Maintain good posture to reduce extra strain on your body. This will also help you breathe easier.
- Avoid exercises that require quick bursts of energy.

## Your Exercise Program

Begin a program of aerobic exercise. Walking, cycling, and swimming are types of aerobic exercise. Slowly increase the time, distance, and pace that you exercise. Your nurse and doctor can help you plan your exercise program.


Follow these guidelines:

- Exercise at the level recommended by your doctor or nurse.
- Wait 1 to 2 hours after a light meal to exercise. Do not exercise on an empty or full stomach.
- Avoid exercising outside when it is less than 40° or greater than 80°.
- Warm up and cool down with stretching and slow walking.
- Adopt a slow, steady, rhythmic pace.
- Avoid exercise that involves lifting weights over 5 pounds.
- Remember to choose a mid-point for your exercise. If you go for a walk, be sure to turn around so that you will have enough energy to get back where you started.
- Watch for signs of over-exertion. If you have any of these during exercise, slow down. If the symptoms don't ease, you need to stop. If you still have symptoms after stopping for 5 minutes, call your doctor.
  - Excess shortness of breath to the point of not being able to complete a sentence
  - Dizziness, lightheadedness
  - Chest pain or tightness
  - Irregular heart beat (pulse)
  - Pain in your arms, shoulders, neck, or jaw; or a severe headache
  - Unusual or extreme fatigue
  - Severe sweating
  - Upset stomach, vomiting



### Warm-up and Cool down Exercises

Do these exercises about 10 times each before and after exercising.

<p><b>Lateral Neck Flexion</b></p>  <p>Tilt head toward shoulder then tilt head toward the opposite shoulder.</p>	<p><b>Neck Rotation</b></p>  <p>Turn head slowly over each shoulder.</p>
<p><b>Neck Flexion</b></p>  <p>Slowly bend head forward, then return to starting position.</p>	<p><b>Shoulder Shrugs</b></p>  <p>With arms relaxed at sides, raise shoulders, then relax.</p>
<p><b>Shoulder Rolls</b></p>  <p>Roll shoulders slowly backward, and then roll shoulders forward.</p>	<p><b>Sitting Knee Flexion/Extension</b></p>  <p>Slowly straighten one knee and then return foot to the floor. Switch legs and repeat</p>
<p><b>Sitting Toe Raises</b></p>  <p>Raise toes off floor while keeping heels on the floor.</p>	<p><b>Sitting Marching</b></p>  <p>March in place while sitting.</p>

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## Your Body Weight

Weighing a normal body weight for your height is important when you have heart failure. Weighing more means your heart has to work harder. Weight loss will reduce how hard your heart must work.

The key is to eat less and exercise more. Cut back on your serving sizes. Limit sweets and fatty foods. These have lots of calories but not much nutrition value. Any fat has more than twice the number of calories of other foods.

Talk to your doctor, nurse, or dietitian if you need extra help in losing weight. You may also find a buddy system works well for you, so team up with a friend or family member who has a similar weight loss goal. Weight Watchers® and other weight-loss programs that offer support and good nutritional advice may also be helpful.

## Smoking

If you smoke, it is important to quit. Smoking makes the heart work harder, which is especially harmful when you have heart failure. If you smoke, please talk with your doctor and nurse for helpful information on quitting.

## Alcohol

Alcohol decreases the ability of the heart to pump. Alcohol use is discouraged with heart failure. Alcohol may interact with the medicines you are taking. Talk with your doctor or pharmacist. If you choose to drink:

- Drink no more than 1 drink per day
- One drink equals 12 ounces of beer (1 can or bottle), 4 ounces of wine (1 wine glass), or 1 ounce (1 shot) of hard liquor such as whiskey or vodka.

## Fluid

Most people with heart failure can drink normal amounts of fluid. Some people are told to restrict their fluid intake.

If told by your doctor, restrict fluids to \_\_\_\_\_/day.

But, everyone with heart failure should avoid excess fluids. To do this:

- Space out your fluids throughout the day.
- Avoid drinking large amounts of fluid all at once.

## Your Treatment Plan

Following your treatment plan with care could pay off for you. Make it a permanent part of your life. By following this treatment plan, you could:

- be more active,
- improve your quality of life, and
- possibly live longer.

We know that following this treatment plan can be hard. Sometimes the cost or side effects of medicines can be discouraging. Remembering to take all of your medicines, sticking to your diet changes, and finding the energy to exercise can seem like too much. Talk to your doctor or nurse for help if you are having trouble sticking to your treatment plan. They can offer suggestions and work with you to find solutions.

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### Remember to:

- Take your medications every day as directed by your doctor.
- Not use salt and avoid foods with a lot of salt.
- Weigh yourself every day at the same time.
- Call your nurse or doctor if you have:
  - Weight gain of 2-3 pounds overnight or 5 pounds in a week
  - Problems breathing at night
  - Increasing shortness of breath, coughing, or wheezing
  - Coughing without flu symptoms
  - More swelling than usual
  - A feeling of being more tired than usual
  - Less energy and are less active than usual
  - New chest pain or chest pain like you have had before that does not go away with nitroglycerin
- Call your doctor if, while taking Digoxin, you have:
  - Loss of appetite, distaste for food, or bad taste in the mouth
  - Upset stomach or vomiting
  - Bluish or yellowish vision
  - Skipped heartbeats, dizziness, palpitations, or rapid heart beating
- Call your doctor if, while taking diuretics, you have:
  - Increasing dizziness
  - Severe weakness
  - Severe leg cramps

### To contact your doctor or nurse:

Nurse's Name \_\_\_\_\_

Nurse's Phone Number \_\_\_\_\_

Doctor's Name \_\_\_\_\_

Doctor's Phone Number \_\_\_\_\_